Priority Setting in Action: using web-based surveys

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Our partnership

Cochrane Epilepsy

Cochrane Movement Disorders

epilepsy action

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

www.epilepsy.org.uk
Sally Crowe

www.parkinsons.org.uk
Kristina Staley
This presentation – how we did it

1. Task & development
2. Approach
3. Analysis & impact
4. Learning
This presentation

We aim to share our experience of

- Thinking through and developing an approach to topic refinement
- Developing web-based surveys and promoting participation
- Reflection on our experience
Our task

Seek stakeholder’s preferences for Cochrane systematic reviews:

- **topics** relating to interventions and care
- **outcomes** to used or aspects of care for consideration in the reviews

We call this **topic refinement**

Our NIHR programme grant was awarded to support development of a **specified** number of reviews from 2 Cochrane Groups:

- Epilepsy & Movement Disorders
Development – step 1

I had a think...
Development – process driven
Development – extensive approaches

The Cochrane Tobacco Addiction Group (TAG) Anniversary and Priority Setting Workshop
Development – reference methods
Alcohol-Related Liver Disease PSP Project plan  
(For information, a typical PSP completes in around 12-18 months)

|------|------|-------------------|--------|---------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|

“a typical PSP completes in around 12-18 months”
Development – consider the journey
Development – consider value

Perfect is the enemy of good?
Development – other steps

I thought…
I read…
I shared…
I did…
Overview - priority setting approaches

**Technical**
- Use of existing data e.g. disease prevalence, economic burden, other measures
- Scoring and use against matrix of criteria
- Gap analysis or identified need e.g. Guidance and policy plans, commissioning health services
- Systematic review of existing priority sets
- Horizon and environmental scanning
- Cochrane criteria (e.g. downloads) or editorial decisions

**Interpretive**
- Surveys to generate/ rank/ validate priorities (Delphi or other)
- Using ‘free text’ data to inform above
- Creating/enriching scenarios to inform research topics and priorities
- Discussion among informed stakeholders to generate and or agree priorities; workshops, meetings.
- Accessing patient narratives, help line data and proxy sources of perspectives
Approach – overview

Developed and piloted a 2 web-based surveys:
  - Epilepsy
  - Parkinson's Disease

Topic lists from editorial base teams

Worked closely with a small selection of epilepsy and Parkinson’s organisations

Developed a digital media strategy to promote the surveys

No workshops or face-to-face meetings scheduled
Approach – promotion (1)

The Cochrane Epilepsy Group have been awarded funding to produce some new and some updated systematic reviews on epilepsy.

We are running a focused topic prioritisation activity to help us decide on important topics for new and updated systematic reviews. We will use a short online (print on request) survey to collect views on a short list of systematic reviews to begin or update as well as suggestions for other topics for systematic reviews (in addition to the short list). The survey will also ask for key reasons why you think topics are important.

The method is similar (but much less detailed) to James Lind Alliance approaches. We have also searched for reports of other prioritisation exercises to help inform the process and avoid duplication of effort.

epilepsy.cochrane.org/news/topic-prioritisation
Approach - promotion (2)

- Accessed ‘research interested’ networks using targeted direct mail:
  - EA 8000 list members
  - PUK 4500 list members
- Our Cochrane groups emailed their members
- Cochrane & partner social media support
Approach – promotion (3)

Do you have experience of Parkinson's disease?

https://spark.adobe.com/video/LojNYUy3nLoli

https://spark.adobe.com/video/Qhc6vEwBg6Eaa
Approach – promotion (4)
Approach – survey structure

**Promotion**
- Stakeholder email
- Social media
- Webpage visits

**Information**
- Prioritisation
- Systematic reviews
- Survey instructions

**Consent**
- Participant information
- Consent form
- Tick box confirmation
Approach – survey structure

Top 10
- Select up to 10 topics
- Select 1 other topic

Top 5
- Select up to 5 topics
- Can include the other topic

Rank
- Rank up to 5 topics

Reasons
- Reasons for selecting top 5 topics

Add topics
- Option to add topics
- Plus reasons why/ rank

About you
- Experience of the condition
- Location
- Quality assurance Q
Approach - survey introduction

Welcome to our short survey

In the survey, you will be asked to share your views on top priorities for research using systematic reviews. There are 6 steps:

1. Select up to 10 top topics
2. Select up to 5 top topics
3. Rank your top topics
4. Tell us more about your choices
5. Add other topics & tell us more
6. About you (optional) & submit

Thank you for participating. Your views are important.

The Cochrane Epilepsy Group asks for your help to identify the most important topics for updated and new systematic reviews on epilepsy.
Approach – survey steps

https://www.surveymonkey.co.uk/r/CochraneDemo
The survey – some features/ functions

General approach

- Mix of closed form, ranking and open form items on topics
- Prioritisation using a sequence of selecting:
  - top 10 → then top 5 → then ranking the top 5

Technical details*

- Used the survey platform’s response ‘carry forward’ functionality
- Topics initially presented to respondents in random order
- Survey split into ‘pages’ to allow data capture without respondents reaching end page
- Demographic questions at end and deliberately restricted in detail

* WARNING – if you ask me about these, I will talk your ears off
Approach – random order, bulk answers

https://www.surveymonkey.co.uk/r/CochraneDemo
Approach – carry forward

https://www.surveymonkey.co.uk/r/CochraneDemo
Analysis & impact - reach

- Largely UK-based respondents
- Over 1000 respondents:
  - 569 started the epilepsy survey
  - 470 started the Parkinson’s survey
- Majority of respondents were people with the condition:
  - 59% epilepsy
  - 78% Parkinson’s
- Few responses from professionals
Analysis & impact – top 5 (epilepsy, PD)
Different patterns in responses between epilepsy and Parkinson’s disease

- **Epilepsy** – ‘cluster and cliff’
- **Parkinson’s** – *more* evenly distributed

Priorities generally consistent across top 5 and ranking scores

Rich information source in reasons why free text

- Some relatively simple, reflecting personal experience
- **Epilepsy** – “People are going nuts about CBD, presuming it will work for them and taking any form of cannabis that they can…”
- **Parkinson’s** – “Anxiety has been the most distressing element on a day to day basis of my Parkinson's. Even being unable to walk properly is easier to deal with.”
Learning – Cochrane KT guidance

**Governance** – team to develop the process
Shortlist by Cochrane groups, with external stakeholder reps. Refinement involved external experts & stakeholder reps.

**Stakeholder engagement** – external & internal to Cochrane
External: people with lived experience via email & social media - reasonable numbers & diversity, some health professionals. Internal: via Cochrane group authors email, Consumer Facebook & KT group

**Documentation & dissemination**
Process & findings to be written-up & disseminated (plus conferences, webinar). Priorities informed programme planning

**Currency & timeframe**
Current for 2018-21
Learning – REPRISE checklist

1. **Context and scope** – UK based, interventional questions, SRs, epilepsy and Parkinson’s disease, medium term priorities.
2. **Governance and team** – internal team referred to throughout, could have had more external members, some team members experienced in priority setting.
3. **Inclusion of stakeholders** – lived experience and specialist professionals (limited information), aim for 300 in each survey, no reimbursement for participation.
4. **ID and collection of topics** – previous prioritisation exercises, online survey, gathering topics in addition to set for prioritisation, known unknowns.
5. **Prioritisation of topics** – individual ‘forced’ online ranking, exclusions of other questions yet to be determined.
6. **Outputs** – Epilepsy ranked set, Parkinson’s Disease less distinct priorities.
7. **Evaluation and feedback** – currently in this phase.
Learning – key reflections (1)

- Navigating from ‘gold’ to ‘good’
  - Thinking about goals, ‘distance’, support and value
  - Broadly in line with prioritisation guidance
- **Staging** approaches – topic shortlists, web-based approaches, workshops held in reserve
  - Remote approach, but good reach and interactive, consumer driven elements
- **Focused** engagement with a selection of stakeholders
- **Engaging** target audience in testing and improvement of surveys
- Integrating other *topic research* – reasons why
- **Defining** ‘systematic review’ – not easy!
Learning – key reflections (2)

- Managing **information shared** by people with a condition
  - Data governance and legislation – care needed
  - Resource to analyse
- Choosing **digital tools**
Learning – your views…

- In what ways could we have done this better?
- Was the approach **good enough**?
- What would you **want to know** in a report/publication?
- How should we disseminate?
- Is the lack of professional respondents an issue?
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Declaration of interests, funding and acknowledgements

Ruaraidh
- Financial – non personal, non specific interest. Delivered educational workshops on health economics, medicines management and HTA for cancer specialists – unrestricted sponsorship by pharmaceutical industry and industry association (March 2019). Not specific to topics presented.

Cochrane author

Sally, Kristina
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Ethics
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